

HIV Health Care Access Working Group

**Statement to Senate Finance Committee Members
Relating to the May 14, 2009 Description of Policy Options
Expanding Health Care Coverage:
Proposals to Provide Affordable Coverage to All Americans
May 22, 2009**

Dear Chairman Baucus and Ranking Member Grassley:

We are writing on behalf of the HIV Health Care Access Working Group ("HHCAGW") to offer comments to the Senate Finance Committee on the policy options outlined in *Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans*. HHCAGW is a coalition of eighty-four national and community-based AIDS service organizations representing HIV medical providers, advocates and people living with HIV/AIDS and providing critical HIV-related health care and support services. The Working Group is actively engaged in efforts to increase early and affordable access to quality, comprehensive care for people living with HIV/AIDS. We urge the Committee to consider the following recommendations for addressing current barriers to access to health care coverage.

SECTION I: INSURANCE MARKET REFORMS

Significant market reforms are needed for the private insurance market to work for people with HIV and other individuals with chronic conditions that have intense medical needs. We offer support and recommendations below.

Non-Group and Micro-Group Market Reforms

- We strongly support the proposal to eliminate pre-existing condition exclusions (pp.2-3). This reform measure is absolutely vital to create a health care system that supports the delivery of cost effective health care.
- Risk-adjusted payments to private plans are critical to ensuring access to private market coverage for people with HIV (p.3). We strongly recommend that the Secretary set the risk adjustment levels to ensure equitable payments across the country.
- We oppose the proposal to adjust premiums according to age or tobacco use (p.3), as it would perpetuate financial barriers to accessing coverage.

Health Insurance Exchange

- We recommend against using marketing guidelines for Medicare Advantage as a model for the exchange (p.5), as seniors and people with disabilities have been seriously misled under these guidelines. Instead, we urge you to look to states such as California for models for regulating marketing by private insurers.
- We urge for Exchange policies and regulations to be standardized by the Secretary wherever possible, and oppose establishing multiple exchanges (p.6)—an approach that would make an already complex system even more difficult to navigate. The failures of

Medicare Part D, for instance, indicate that a reformed system must be user-friendly and easy to navigate.

SECTION II: MAKING COVERAGE AFFORDABLE

HHCAGW supports increasing the range of affordable, comprehensive health insurance options for all individuals. In the context of the Committee's proposal to establish an Exchange through which individuals and families could purchase private health insurance, we offer the following suggestions:

Benefit Options

- HHCAGW supports the Committee's proposal to establish a mandatory minimum benefits package for health insurance plans available through an Exchange (p.9). In addition to the proposed categories of mandatory medical services, health insurance plans must also be required to cover optical, dental, home health and rehabilitation services. These services are necessary to promote and maintain wellness—particularly for individuals with chronic, complex health conditions whose medical expenses are high and cannot afford to pay out-of-pocket for these important services.
- We recommend that “voluntary routine HIV testing and counseling” be included in any preventive care and in any screenings in all health insurance plans (p.9).
- We strongly support the proposal to prohibit the following: lifetime limits on coverage; annual limits on benefits; and any cost-sharing for preventive care services in health insurance plans offered through an Exchange (p.9).
- We are concerned that the Committee is recommending prescription drug coverage be modeled after the Part D formulary and class requirements (p.9). We strongly urge you to specify that plans would be required to cover other Part D formulary requirements, such as the requirement that plans are required to cover all or substantially all of the medications in the 6 protected classes of drugs under Part D (antidepressant; antipsychotic; anticonvulsant; immunosuppressant; antiretroviral; and antineoplastic), and are barred from applying utilization management techniques such as prior authorization to the antiretroviral drug class.
- It is essential that any cost-sharing system—for prescription drugs and/or for the treatment of conditions within the four enumerated categories of benefits (p.9)—include reasonably affordable caps on consumers' out-of-pocket expenses. HHCAGW supports an income-adjusted cap on out-of-pocket cost-sharing and co-payment expenses.

Low-Income Tax Credits

- HHCAGW supports providing premium subsidy-tax credits to enable low income individuals and families to affordably access health insurance through an Exchange (p.11). However, we strongly oppose using MAGI as the basis for determining premium subsidy-tax credits (p.11). MAGI uses factors relevant to higher-income individuals and ignores financial realities facing working-class families—such as public benefits and child support, medical and work-related expenses—that must be accounted for as exclusions or deductions in the determination of income. We understand that the Committee aims to apply a uniform income determination for evaluating eligibility for Medicaid and premium subsidy-tax credits. But as both of these benefits are designed to assist low-income populations, it makes more sense to use an income determination—such as that currently used by the Supplemental Nutrition Assistance Program (food stamps)—that accounts for financial matters that low-income and

working-class families commonly face. Using MAGI in this context would unfairly and artificially reduce eligibility for low-income tax credits and Medicaid.

- If an Exchange system is established, HHCAGW supports a sliding scale-based premium subsidy-tax credit for individuals and families up to 400% FPL to purchase health insurance. However, two important modifications to the proposed low-income tax credit structure are necessary to ensure that low-income individuals and families have adequately affordable access to private plans through an Exchange. First, a full premium subsidy must be available to individuals and families up to 200% FPL. Second, all subsidies should be provided for high-level coverage for everyone under 400% FPL, rather than stepping coverage levels down for individuals and families at 200-400% FPL and requiring people in that income bracket to pay out of pocket for higher-level coverage as is proposed (pp.11-12). Reducing coverage levels based on nominally higher income is particularly burdensome to and unfair for people who have intense health care needs.
- In addition to premium subsidy-tax credits, we support providing income-adjusted cost-sharing assistance to low-income families who purchase health insurance through an Exchange if cost-sharing is not capped as suggested above (see Benefits Options, fifth bullet).

SECTION III: PUBLIC HEALTH INSURANCE OPTION

- We urge the Senate to create a public health insurance option such as the Medicare-like plan described in Approach 1 (p.13). We discourage the Senate from hamstringing the plan with requirements that are appropriate for a well-regulated private insurance market, but are not relevant to a government program. For instance, Approach 2 (p.14) would add an unnecessary layer of bureaucracy and create impediments to the plan's ability to succeed. We oppose Approach 3 (p.14), as it would simply dump the problem of hard-to-insure people on the states and offers no solution to the health care crisis.

SECTION IV: ROLE OF PUBLIC PROGRAMS

The Medicaid and Medicare programs play a vital role in ensuring access to lifesaving care for people with HIV, and we strongly support reforms that will strengthen and enhance the public health care system.

Medicaid Coverage

Eligibility Standards and Methodologies

- We urge you to build on the Medicaid program to provide coverage to all low income individuals by eliminating the categorical eligibility requirement or adding a new mandatory category for childless adults. We are concerned that different sections of the paper treat childless adults differently, and there is no clear call for Medicaid to cover childless adults (pp.15, 17, 41). Medicaid's benefits package and cost protections are vital to ensuring that low income individuals have affordable access to the services they need to stay healthy.
- We recognize the need to align income standards between eligibility for Medicaid and eligibility for credits to purchase coverage through an Exchange. But we oppose the proposal to base income determinations on MAGI and eliminate income disregards under Medicaid (p.15), as income levels of 150% FPL (around \$16,000/year) are still lower than the standard of living in most parts of the country. And, as discussed above under Section II, MAGI favors income deductions that, while useful to higher income taxpayers, ignore

deductions and exemptions, such as certain public benefits, work-related expenses, and child support that are vitally important to lower and middle income families.

- We urge you to incorporate the Early Treatment for HIV Act (S 833) into your health care reform proposal to grant states the option to cover people with HIV under Medicaid at higher income levels. Medicaid's comprehensive benefits package and cost sharing protections are vital to individuals with HIV at higher income levels.

Medicaid Program Payments

- We oppose the proposal to set Medicaid rates at 80% of Medicare rates (p.16) because this rate would be insufficient to support the cost of delivering health care and will perpetuate lack of access to the expert care that is critical to the effective management of HIV care. We urge the Committee to amend this proposal to require that states pay Medicaid providers at Medicare rates.

Treatment of Territories

- We strongly support bringing Medicaid eligibility and financing in the territories in line with the states (p.19). The current approach has compromised the health and well being of many people with HIV living in the territories.

Other Improvements to Medicaid

Enrollment and Retention of Simplification

- We strongly support efforts to streamline Medicaid enrollment and retention processes by eliminating face-to-face interviews and the asset test in addition to establishing a 12-month continuous eligibility requirement (p.23). These simple but important policy changes will contribute to lower administrative costs and improved continuity of care and coverage for Medicaid beneficiaries, including people with HIV.
- We strongly recommend further streamlining and improving Medicaid and CHIP by developing a uniform application for each program that could be adopted across the states, and by requiring recognition of eligibility in these programs when beneficiaries move or are temporarily out of state. Interstate coordination should include all beneficiaries, not only children as proposed (p.25).

Treatment of Selected Optional Benefits

- We strongly support granting provider status to podiatrists and optometrists (p.24). We urge you to also grant provider status to psychologists. These providers' services play a critical role in the HIV care system.

Mandatory Coverage for Prescription Drugs

- We strongly support the proposal to make prescription drug coverage a mandatory benefit under Medicaid (p.26). Prescription drugs are the crux of HIV treatment—barriers to accessing physician-recommended drugs leads to higher-cost interventions, such as hospitalization, for people with HIV.
- In addition, we urge you to bar states from applying arbitrary limits to their prescription coverage. Currently, a few states have limits that do not support the standard of care for HIV. For example, Texas has a three prescription drug limit per month and Mississippi has a two drug limit on brand name drugs and a three drug limit on generic drugs per month. It is more cost effective and better for both individual and public health to cover the cost of drugs that prevent and treat serious illness.

Change the Status of Some Excludable Drugs

- We strongly support the proposal to eliminate the exclusion of smoking cessation drugs, barbiturates, and benzodiazepines from Medicaid coverage (p.27).

Transparency in Medicaid and CHIP Section 1115 Waivers

- We agree with the proposal to require increased transparency and ensure opportunities for public input when states are developing Medicaid and CHIP section 1115 waivers (pp.28-29). Stakeholders should have the opportunity to monitor and contribute to the development of waiver proposals, as they can effect sweeping changes to the public safety net program.

Automatic Countercyclical Stabilizer

- We strongly support the call for the FMAP to automatically increase during economic downturns, as demand for Medicaid services increases during difficult economic times (p.31). It is critical that Medicaid programs continue to be able to meet the need for health care without compromising eligibility, benefits or provider reimbursement.

Dual Eligibles

- We support proposals to improve coordination and outcomes for people dually eligible for Medicaid and Medicare and granting greater attention to improving their care through demonstration projects and a dedicated office at CMS (p.36). Nearly 80,000 people with HIV fall into the dual eligible category and are currently particularly vulnerable to falling through cracks in the health care system.

Medicare Coverage

Reduce or Phase-Out the Medicare Disability Waiting Period

- The waiting period is a dangerous window in time for people with HIV, whose lives depend on ongoing, reliable access to health care services. We strongly support the immediate, full elimination of this inefficient and potentially deadly gap in coverage. If an immediate elimination is not fiscally possible, we strongly urge you to move forward with Approach 3 (p.38) that would phase out the waiting period in six month increments until fully eliminated in April 2011.

Temporary Medicare Buy-In

- We strongly support offering individuals between the ages of 55 and 64 the opportunity to buy in to Medicare (p.39). We urge you to ensure that the coverage is affordable to make it a viable option for individuals in this age group, which is particularly vulnerable to losing coverage in the private market. We also urge you to extend the buy-in period given the high premiums that individuals in this age group would be subject to in the private market under the proposed 5:1 age rating.

Medicare Part D *(represents addition to the Committee's policy proposals)*

- We are concerned that Medicare Part D reforms are not addressed in this policy paper. Medicare Part D has failed many people with HIV and other low income seniors and people with disabilities. We urge broad reforms that include offering a public drug benefit option, limiting cost sharing and closing the gap in coverage. In the short-term, we urge you to consider a simple and inexpensive policy change that would be lifesaving for individuals with HIV: allow contributions made by AIDS Drug Assistance Programs (ADAP) to count toward the true out-of-pocket limit under Medicare Part D. Given the current economic situation, it is increasingly difficult for ADAPs to fill in the Medicare coverage gap. Furthermore, in most

states individuals lose access to non-HIV drugs when they enter the donut hole and their coverage is transferred to their state ADAP.

SECTION VI: OPTIONS TO IMPROVE ACCESS TO PREVENTIVE SERVICES AND ENCOURAGE HEALTHY LIFESTYLES

It is estimated that 231,000 people (21 percent or of the total number of people living with HIV/AIDS in the United States) are unaware that they are HIV-positive. These individuals account for 54 to 70 percent of new HIV infections. Routine HIV testing is an important tool for reducing the number of new infections. People who know their HIV status are less likely to engage in behaviors that could transmit the virus. Additionally, routine testing fosters early diagnosis and linkage to care which improves patient outcomes. Early treatment not only reduces a patient's viral load and infectivity but it is also cost effective. Since September 2006, the Centers for Disease Control and Prevention (CDC) has recommended voluntary HIV testing as part of routine medical care for people ages 13 to 64 in all health care settings.

Despite the availability of innovative HIV therapies that have made HIV a chronic and more manageable condition for many, far too often people with HIV are diagnosed late in their illness. Thirty-six percent of people with HIV in the U.S. progress to AIDS within one year of diagnosis, indicating a very late diagnosis. Individuals diagnosed late have much poorer health outcomes and cost 2.6 times more per year to treat.

Lack of reimbursement by public and private payers is a major barrier to implementing CDC's recommendations for HIV screening. HHCAWG strongly supports a federal mandate that private insurers as well as the Medicaid and Medicare programs cover routine, voluntary HIV testing and counseling. Therefore, we urge you to explicitly include routine, voluntary HIV testing and counseling in each of the policy options you have outlined that relate to coverage for screenings and prevention programs. Specifically, we recommend providing for increased access to routine, voluntary HIV testing and counseling by adopting the measures described below, as well as by including "voluntary routine HIV testing and counseling" in any preventive care and/or screening requirements in all health insurance plans (See above, Section II "Benefit Options):

Promotion of Prevention and Wellness in Medicare

Personalized Prevention Plan and Routine Wellness Visit

- We recommend the inclusion of voluntary routine HIV testing in the comprehensive health risk assessment that is proposed to be offered every five years (pp.43-44). We support the proposal that no co-payment or deductible would apply for these prevention services (p.44). If during this health risk assessment the beneficiary is deemed to be at risk for HIV, we recommend that Medicare ensure that HIV education and counseling be included. Furthermore, the health risk assessment shall not minimize access to testing for a person who is deemed to be at low risk for HIV. A person who is deemed at low risk of HIV infection shall not be discouraged or denied a HIV test. For all beneficiaries receiving a personalized prevention plan, we expect that the CDC recommendations for voluntary routine HIV testing be followed.

Incentives to Utilize Preventive Services and Engage in Healthy Behaviors

- We recommend the inclusion of voluntary routine HIV testing and counseling as one of the preventive services for which beneficiary cost-sharing would be removed or limited (p. 45).

Coverage of Evidence-Based Preventive Services

- We oppose the proposal to give the Secretary authority to withdraw Medicare coverage for preventive services that are rated “D” by the United States Preventive Task Force (USPSTF) unless deemed medically necessary by a prescribing physician (p.45). There are a number of instances in the areas of routine HIV screening as well as screening for hepatitis B and hepatitis C where USPSTF recommendations are in direct conflict or are silent on current CDC recommendations. We are concerned that preventive services on which USPSTF and CDC recommendations disagree or where USPSTF is silent will not be covered by Medicare, Medicaid, or public and private plans under the proposal. Particularly as the USPSTF is not always current in its recommendations, we strongly recommend that where the USPSTF is silent, preventive services recommended by APIC or the CDC be reimbursed. This approach has precedent in USPSTF's deference to the CDC's and the Association for Practitioners in Infection Control's (APIC) recommendations on TB screening and adult and child immunizations.

Promotion of Prevention and Wellness in Medicaid

Access to Preventive Services for Eligible Adults

- Due to the growing number of new HIV infections in the United States (over 56,000 annually) and the high number of people who are undiagnosed—many of whom rely on Medicaid for their healthcare—we strongly recommend including routine, voluntary HIV testing and counseling as one of the screening and preventive services in Medicaid (p.46) consistent with the CDC's recommendation that voluntary routine HIV testing be offered to all persons ages 13-64 in healthcare settings.

Incentives to Utilized Preventive Services and Encourage Healthy Behaviors

- We recommend the inclusion of voluntary routine HIV testing and counseling as one of the preventive services for which beneficiary cost-sharing would be removed or limited (pp.46-47).

Prevention and Wellness Trust *(represents an addition to the Committee's policy proposals)*

While we recognize that public health is not under the jurisdiction of the Committee and therefore not addressed as a policy option, we support establishing a Prevention and Wellness Trust with dedicated funding. The Trust Fund would support expansion of public health functions and services that surround, support, and strengthen the health care delivery system to reduce the costly societal expenses of chronic and infectious disease. It would finance:

- The core governmental public health functions of assessment, assurance, and policy development at the federal, state, and local levels.
- Population-level non-clinical prevention and wellness programs that can be delivered through both governmental and community-based agencies, including programs that integrate community-based prevention with systems of medical care.
- Address health disparities by addressing the underlying causes of death, disability, and infectious and chronic disease.
- Clinical preventive services delivered in community settings or by health departments that are not covered by third party payers.
- Workforce training and development, as well as public health research.

SECTION VII: LONG TERM CARE SERVICES AND SUPPORTS

Reforms to long-term care are a critical component of developing a more cost effective and humane health care system. We focus our comments on the Medicaid-related proposals because of their relevance to people with HIV but support much broader reforms to improve access to long-term care services and supports.

Medicaid Home and Community Based Services Waivers (HCBS) and the Medicaid HCBS State Plan Option

- Home and community-based waiver program have been critical to providing the range of services that help people with HIV stay healthy and live in the community while avoiding more costly levels of care. We are very supportive of efforts to expand access to these services. In this vein, we support the proposal to allow states to seek approval to cover additional services under HCBS programs and to allow individuals to enroll in more than one waiver program (p.50).

Eligibility for HCBS Services

- We strongly support the proposal to eliminate the institutional level-of-care requirement for eligibility for HCBS services (p.51). This change is a positive step in transforming our system from a disability care system to a health care system that supports early interventions that prevent serious illness.

SECTION VIII: OPTIONS TO ADDRESS HEALTH DISPARITIES

We strongly support the proposal to begin to address health disparities by collecting data that will help to evaluate access to services and health outcomes. It is critical to be fully inclusive with health care reform and ensure that the health care needs of lesbian, gay, bisexual, and transgender (LGBT) individuals are addressed. HIV disease continues to disproportionately impact gay men. It is vital to assess their access to care and health outcomes in communities across the country in addition to addressing health care access and outcomes broadly for the LGBT community. Disclosing this information must be voluntary for individuals seeking services—not a requirement for care.

Required Collection of Data

- We urge you to require SSA to collect data on Medicare enrollees' sexual orientation and gender identity in addition to race, ethnicity and language (p.57).

Data Collection Methods

- We recommend expanding the MIPAA proposed uniform categories to include sexual orientation and gender identity (p.58). Require the Secretary to include sexual orientation and gender identity among the categories being evaluated to measure disparities in the health care and performance of the Medicare program. We also recommend modifying language in the Health Information Technology for Economic and Clinical Health Act (HITECH) to require the inclusion of sexual orientation and gender identity as part of the patient demographic data as standard for HIT systems.

Standardized Categories for Data

- We recommend expanding the proposed uniform categories to include sexual orientation and gender identity (p.59).

Elimination of Five-year Waiting Period for Non-Pregnant Adults

- We strongly support the proposal to add non-pregnant adults to the list of Medicaid beneficiaries for whom states would be permitted to waive the waiting period that currently bars legal immigrants from accessing Medicaid coverage for five-years (p.61).

Thank you for the opportunity to comment on this important matter as the Committee investigates health care reform. For more information, please contact HHCAWG co-chairs Laura Hanen of the National Alliance of State and Territorial AIDS Directors at (202) 434-8091 or Robert Greenwald of the Treatment Access Expansion Project at (617) 390-2584.

Sincerely,

HIV Health Care Access Working Group Steering Committee

AIDS Action, Washington, DC

AIDS Action, Baltimore, MD

AIDS Alliance for Children, Youth and Families, Wash., DC

AIDS Foundation of Chicago, Chicago, IL

The AIDS Institute, Washington, DC

AIDS Project Los Angeles, CA

American Academy of HIV Medicine, Washington, DC

Broward House, Ft Lauderdale, FL

Community Access National Network, Washington, DC

Community HIV/AIDS Mobilization Project, New York, NY

Gay Men's Health Crisis, New York, NY

Health & Disability Advocates, Chicago, IL

Housing Works, New York, NY

Indiana Minority Health Coalition, Indianapolis, IN

Lifelong AIDS Alliance, Seattle, WA

National Alliance of State and Territorial AIDS Directors, Washington, DC

National Association of People With AIDS, Silver Spring, MD

National Minority AIDS Council, Washington, DC

New York AIDS Coalition, New York, NY

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